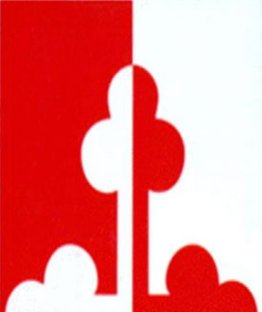








MARYLAND STATE SCHOOL HEALTH SERVICES GUIDELINE



MANAGEMENT OF SICKLE CELL DISEASE IN SCHOOLS



JUNE 2019



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FOREWORD

There is a strong relationship between academic achievement and a child’s physical, emotional, and mental health. This link is the foundation for providing school health services as an important component of a school program. School health services provide primary prevention aimed at keeping students in schools through appropriate screenings, early identification of students at risk for physical, emotional and mental health concerns, and case management of students with chronic health concerns.

The Annotated Code of Maryland, Education Article, § 7-401 requires the Maryland State Department of Education (MSDE) and the Maryland Department of Health (MDH) to jointly develop public standards and guidelines for school health programs. The guidelines developed under § 7-401 contain recommendations for minimum standards of care and current best practices for the health service topics addressed. The following *Maryland State School Health Services Guideline – Management of Sickle Cell Disease in Schools* (Guideline) was developed in accordance with that requirement and is based on the expressed needs of the local school health services programs. It is intended that this Guideline will be used by the local school systems in developing local school health services policies and procedures to provide consistent and safe care to the students of Maryland. Specific laws and regulations that direct school nursing practice or other health services are identified in the Guideline.

In 2018, the Maryland General Assembly enacted a new law governing the care of students with sickle cell disease. The law can be found in the Annotated Code of Maryland, Education Article § 7-444. The law requires the MSDE and MDH to establish certain guidelines for public schools, to provide technical assistance on the implementation of the guidelines, and develop a process to monitor implementation of the guidelines. To implement these guidelines, local school health services programs should recognize the role of the school health services coordinator as required under the Annotated Code of Maryland, Education Article, § 7-401(c)(2)(ii), to “ensure that public schools adhere to local health services guidelines.” Local school systems and local health departments should support the role of the school health services coordinator to implement these guidelines and consult with the MSDE and the MDH who will:

- Assist and provide technical assistance to local school health programs to support their efforts to plan for students with special health needs;
- Provide training to all appropriate school staff regarding issues related to students with special health needs including, but not limited to, planning, maintaining a safe environment, and medication administration issues; and
- Monitor the implementation of school health services programs, including, but not limited to, programs and policies related to students and staff with special health needs.

This document was developed with the input and review of the State School Health Services Guidelines Committee and key stakeholders specializing in the health care and treatment of children with sickle cell disease. The document represents nursing practice mandates (laws and regulations) consistent with the Maryland Nurse Practice Act. This guideline does not override any existing state or federal laws. Any questions concerning legal obligations should be addressed to the local school system legal counsel.

SECTION I: INTRODUCTION

PURPOSE

The purpose of this guideline is to:

1. Provide guidance for school health services programs for the development and implementation of policies and procedures regarding sickle cell disease.
2. Provide guidance for school nurses on sickle cell disease regarding education, training, environmental assessments, and controls.
3. Define the roles and responsibilities of school health services staff, school administrators, school food service staff, other school staff, parents/guardians, and students in the planning, care, and education of students with sickle cell disease.

BACKGROUND AND SICKLE CELL DISEASE INFORMATION

BACKGROUND

All students have the right to equal access to all school activities and school sponsored events. Any student with a chronic condition such as sickle cell disease cannot be denied access to any school activity based on their needs related to the medical condition.^{1,2,3} Keeping students with sickle cell disease (SCD) safe in school requires procedures for rapid recognition and treatment of symptoms and management of health crises. This requires the development of a SCD individualized health plan (IHP) and emergency care plan (ECP) which may require unlicensed school staff to provide certain SCD care management, when appropriate, in accordance with this Guideline as required by Annotated Code of Maryland, Education Article § 7-444.⁴

When caring for a student with SCD in the school setting, the school nurse is the lead team member in assessing the student's health needs, performing a nursing appraisal/assessment, and developing an individualized healthcare plan (IHP) to meet his/her needs in the school setting based on the nursing assessment and the health care provider orders. The school nurse should refer to the *Maryland State School Health Services Guideline - Nursing Appraisal/Assessment of Students with Special Health Needs* for general guidance on conducting a nursing assessment for students with chronic conditions. Care of the student with SCD is guided by the student's health care provider orders. The school nurse is also responsible for informing and training appropriate school personnel of the special health needs of students with SCD and providing guidance regarding their need for accommodations (e.g., temperature control, hydration, bathroom access, transportation, field trips, and participation in educational activities). Additionally, the school nurse is instrumental in the reinforcement of individualized SCD education and information for the student, family, and school staff.

SICKLE CELL DISEASE

Sickle Cell Disease is a group of inherited red blood cell disorders affecting the protein known as hemoglobin. Hemoglobin functions to move red blood cells through small blood vessels and carry oxygen from the lungs to various organs and tissues in the body. Individuals with SCD produce abnormal hemoglobin called hemoglobin S (HbS) or sickle hemoglobin.⁵ The hemoglobin S present in SCD causes red blood cells to become hard, sticky, and have a sickle or banana shape under certain conditions.⁶ Blood cells that block blood flow deprive the affected organ or tissue of oxygen causing pain and other serious complications.

There are various types of SCD ranging from mild to severe. Each individual with SCD may have a different clinical presentation. The most common type of SCD is known as HbSS. It is inherited when a child receives two sickle genes (“S”), one from each parent. HbSS is known as the most severe form of SCD and is commonly called sickle cell anemia.⁷ HbSC is a form of SCD inherited when a child receives one sickle gene (“S”) from one parent and abnormal hemoglobin, known as “C” gene, from the other parent. This is usually a milder form of SCD. HbS beta thalassemia or sickle beta-thalassemia is another type of SCD occurring when a child inherits one sickle cell gene (“S”) from one parent and one gene for beta thalassemia, another type of anemia, from the other parent. There are two types of beta thalassemia: Sickle Beta Zero Thalassemia (Sickle β^0 Thalassemia) and Sickle Beta Plus Thalassemia (Sickle β^+ Thalassemia). Individuals with Sickle β^0 Thalassemia generally have a severe form of SCD while individuals with Sickle β^+ Thalassemia tend to have a milder form of SCD. There are also a few rare types of SCD known as HbSD, HbSE, and HbSO. Individuals who have these forms of SCD inherit one sickle cell gene (“S”) and one gene from an abnormal type of hemoglobin (i.e. “D”, “E”, or “O”). The severity of these rare types of SCD may vary.

SCD is a lifelong illness. The severity and presentation of signs and symptoms can vary widely from person to person and change over time. The hallmark symptom of the disease is severe acute pain episodes called “vaso-occlusive crisis” (VOC) or “pain episodes.” Pain can have a sudden onset, vary in intensity from mild to severe, and last for hours to weeks. Pain may occur anywhere in the body and may or may not be accompanied by swelling or fever. Acute chest syndrome (ACS) is a serious health problem and a complication of VOC caused by SCD. ACS occurs due to the blockage of blood flow to the lungs. Children with SCD may experience acute lung disease as a result of ACS. ACS also presents very similar to pneumonia and the symptoms include chest pain, coughing, difficulty breathing, and fever. A chest x-ray may further confirm ACS by the presence of a new pulmonary infiltrate. ACS can be life threatening with clinical signs/symptoms ranging from mild respiratory illness to acute respiratory distress syndrome. Thus, ACS should be treated in a hospital setting. Certain factors can increase the likelihood of experiencing a sickle cell crisis. Common sickle cell crisis triggers include, but are not limited to:

- Infections;
- Cold and/or damp conditions;
- Air pollution;
- Dehydrations;
- Extreme physical activity
- Stress

- Sudden changes in temperature;
- Air altitude;
- Use of alcohol;
- Use of caffeine; and
- Smoking.^{8,9}

Children with SCD are also more susceptible to infection. Infection is the most common cause of death in children with SCD. Most children with SCD are vaccinated against infectious organisms and generally take prophylactic penicillin to decrease incidence of infections. Fever is a sign of infection and should be taken seriously. Other health complications include chronic pain, stroke, vision problems, progressive organ damage (most commonly the spleen, liver, and kidney), acute chest syndrome, priapism, pulmonary hypertension, and anemia.^{10, 11}

Although people of all races and ethnicities can have SCD, in the United States SCD is most common among persons of African descent. The condition is also common among persons of Hispanic, Mediterranean, Caribbean, and Asian descent.

SECTION II: MANAGEMENT OF SICKLE CELL DISEASE

Management of SCD is specific to each individual. The goals of a treatment plan are to relieve pain, prevent infection, reduce health complications and hospitalizations, and improve lifespan. Pain medications may vary depending on the range of pain from mild to severe. Daily administration of hydroxyurea can improve the symptoms of SCD and reduce complications when taken regularly.^{12, 13} Blood transfusions may be indicated for children at high risk of stroke. Blood transfusions can also be used to treat other acute complications such as aplastic crisis and acute chest syndrome. Non-pharmacological treatments may include hydration, warm heating pad, adequate rest, and avoidance of extreme temperatures. Bone marrow transplant is the only cure for SCD.

THE NURSING PROCESS RELATED TO STUDENTS WITH SCD

NURSING ASSESSMENT

The school nurse should assess the health needs of students with SCD. The school nurse should use local standard assessment procedures and the procedures outlined in the *Maryland State School Health Services Guideline - Nursing Appraisal/Assessment of Students with Special Health Needs* to conduct the nursing assessment. The school nurse should know and follow the [Family Educational Rights and Privacy Act \(FERPA\)](#), local policies regarding release of records, information sharing, and confidentiality when performing the nursing appraisal, assessment, and health care planning. Information gleaned from the nursing assessment may require additional follow-up to determine if a student qualifies for a Section 504 plan or Individualized Education Program (IEP). The school nurse should follow local school system protocol in communicating this information to the appropriate school officials.

Unpredictable episodes of pain are characteristic of SCD. A “sickle cell crisis” can affect the bones, lungs, abdomen, and joints. Establishing baseline information about the student is essential. Other symptoms of SCD could include, but are not limited to:

- Brain: Headache, stroke, learning disability, learning delay;
- Eye: Visual complaints including floaters, flashes, loss of vision, blurry vision, eye pain, decreased visual acuity, eye redness;
- Skin: Coldness in extremities, pale color;
- Skeletal: Bone or joint pain, cervical spinal pain;
- Respiratory: Shortness of breath, asthma, pneumonia;
- Genitourinary: Frequent urination;
- Spleen: Abdominal pain and tenderness; and
- Liver: Jaundice of the skin and eyes.^{14,15}

Acute illness characteristics of common childhood signs and symptoms, such as fever, cough, abdominal pain, pallor, and extremity weakness, may rapidly progress to a life-threatening

complication in children with SCD. More than one acute complication may occur simultaneously. Examples of acute illnesses that require urgent evaluation and treatment include fever, pain, acute chest syndrome, aplastic crisis, stroke, and priapism. Students diagnosed with SCD need 24-hour access to a medical facility that can provide urgent evaluation and treatment of any acute illness related to SCD.¹⁶

SCD SIGNS AND SYMPTOMS REQUIRING ACTION

| Problem | Signs/Symptoms |
|------------------------------------|----------------------------------------------------------------------------------------------------------------------------------|
| Fever | 101 degrees Fahrenheit (101°F) or greater – seek immediate medical care |
| Pallor or jaundice | Noticeable change in complexion, lips, fingernails, eyes |
| Difficulty breathing | Rapid or difficulty breathing, cough |
| Headache | Sudden or constant onset, acute blurry vision |
| Loss of vision | Changes in visual acuity |
| Change in pulse | Rapid or pounding heartbeat, rapid or bounding pulse |
| Pain | Head, chest, arms, leg, back, abdomen, abdominal distension, priapism |
| Swelling of hands, feet, or joints | Pitting or non-pitting edema, redness, tenderness, and warmth at site |
| Stroke | Muscle weakness on either side of body Facial weakness Arm weakness Speech difficulty Time to call 911 ¹⁷ |

NURSING DIAGNOSIS

After completing the nursing appraisal and assessment, suggested NANDA International (formerly the North American Nursing Diagnosis Association) nursing diagnoses may include, but are not limited to:

- Risk for ineffective tissue perfusion;
- Risk for altered cardiovascular tissue perfusion;
- Risk for activity intolerance;
- Risk for injury;
- Chronic pain, acute pain;
- Fatigue;
- Risk for peripheral neurovascular dysfunction;
- Impaired sensory perception; and
- Potential for impaired social interaction.¹⁸

PLANNING

INDIVIDUALIZED HEALTHCARE PLANS

The school nurse should develop a written individualized healthcare plan (IHP) to provide appropriate SCD management in school. The IHP should be based on the information obtained in the nursing appraisal and assessment and the student's healthcare provider orders. The plan should be developed in collaboration with the student's parent/guardian and the student's healthcare provider(s). The plan should outline the student's needs and the specific interventions appropriate to meet those needs. The IHP is not meant to be a substitute for a Section 504 plan or Individualized Education Plan (IEP). Many of the issues addressed in an IHP should be considered when determining eligibility for, and content of, a Section 504 plan or IEP.

The school nurse should review the IHP at least annually and update as needed. The following information gathered from the nursing assessment should be considered when developing IHPs for students with SCD:

- Student/parent/guardian concerns and expectations;
- Student specific triggers known to cause painful episodes;
- Student specific fever and/or pain management protocol;
- Student's ability to recognize and communicate to designated school staff when experiencing symptoms;
- The student's schedule and activities (e.g., classroom, physical education, lunch, recess, transportation to/from school, school-sponsored activities and events including field trips and after school activities) to ensure student needs are met if school personnel need to be available for SCD management during the school day and other school-sponsored events and activities;
- Medication administration, including:
 - Student's ability to self-manage;
 - Need to delegate medication administration to a CMT;
 - Need to train designated unlicensed school staff (based on nursing judgment and in accordance with the Maryland Nurse Practice Act) to administer medication according to student's healthcare provider orders;
- Needs for immediate access to emergency medication (e.g., emergency plan);
- Developmental factors that facilitate or impede management;
- Knowledge of student's SCD by appropriate school staff, including substitutes;

- The plan to alert and train school staff regarding student’s SCD and expected role in implementation of emergency plan (as appropriate if trained) when the school nurse/school health services staff is not available; and
- Recommended accommodations to communicate to the Section 504 plan team based on nursing assessment and the student’s healthcare provider orders.

SPECIAL CONSIDERATIONS (MEDICAL AND DIETARY NEEDS)

- Hydration, anti-inflammatory agents, and pain medication (i.e. nonsteroidal anti-inflammatory and narcotic analgesia) are helpful during a SCD crisis;
- Working with parents/guardians to ensure immunizations are up-to-date to protect against communicable diseases and infections;
- Consultation with the parents/guardians and the primary care provider may be necessary prior to a student with SCD joining and participating in sports at school;
- Students with SCD do not require a specific special diet, but a well-balanced diet including hydration is important;
- Students with SCD should be allowed to have unrestricted access to drinking water;
- Caffeine should be avoided as it causes the blood vessels to constrict;
- Students with SCD may also be encouraged to wear medical alert bracelets;
- Students and staff must be cognizant of extreme hot and cold weather; and
- Students with SCD may have physical activity limitations.

EMERGENCY CARE PLANS (ECP)

Based on the nursing assessment and the healthcare provider orders, the school nurse should develop an ECP for students with SCD. The plan should communicate how to recognize and treat signs and symptoms of SCD crises. The emergency plan should include, but not be limited to:

- Emergency contact information that is updated as changes occur;
- Healthcare provider's emergency orders/specific emergency interventions needed;
- Recognition of signs and symptoms of SCD crises;
- Procedures for classroom teachers and other school staff to contact the school nurse or other school health services staff in an emergency;
- Who and when to call 911 according to medical orders and local school system policy;
- A list of school staff designated and trained to administer pain medications/treatments, as needed; and
- Plans or strategies for student to self-manage as appropriate.

To facilitate immediate access to emergency care, the school nurse should consider the following when developing an emergency care plan:

- Size and layout of the school building;
- Health services staffing model; and
- Procedures for notifying the nurse of symptoms.

The school nurse should provide a copy of the emergency care plan to the parent/guardian and appropriate school staff who have direct contact with the student (including bus drivers), and place a copy in the student's health record. Providing a copy of the plan to school staff should be in a manner determined by the school nurse to allow immediate access while also protecting the student's confidentiality.

Emergency care plans should also include plans for disaster preparedness in the event of situations such as lockdown, sheltering in-place, and evacuation. Refer to the *Maryland State School Health Services Guideline - Guidelines for Emergency Care in Maryland Schools*. The plan should make provision for SCD management, medications, and supplies needed during a disaster or emergency.

IMPLEMENTATION

The school nurse should follow through on the individualized healthcare plan for each student with SCD. The plan should focus on achievable outcomes in the school setting. The actions involved in the nursing care will include monitoring the student for signs and symptoms of SCD crises or improvement. The school nurse will also educate and train appropriate school staff and serve as a resource to the student and parent/guardian regarding SCD management.

EVALUATION

The student's status and the effectiveness of the nursing care must be continuously evaluated, and the IHP/ECP modified as needed. This includes the following actions by the school nurse:

- Monitoring and evaluating the student's health status;
- Assessing the student's response to and the effectiveness of, the IHP/ECP to meet the student's health and educational needs on an ongoing basis; and
- Making appropriate adjustments to the plans.

SECTION III: CASE MANAGEMENT AND CARE COORDINATION

ROLES AND RESPONSIBILITIES

The school nurse is always the leader of the school health services team. Some students with SCD may have a designated school case manager to coordinate his/her Section 504 plan or IEP. The school nurse also serves as the liaison between the healthcare team, school staff, administration, student services staff, parents/guardians, food service staff, and the student regardless of who is the designated case manager. The school nurse may also refer the student and/or family for counseling, support groups, and medical care. Effective case management requires coordination between all persons involved in the care of the student. Each person or team member has a specific set of responsibilities for the care of the student.

PARENT/GUARDIAN RESPONSIBILITIES

Parents/guardians are integral to the process of planning and coordinating care for all students with special health needs documented by a healthcare provider. In addition, the Annotated Code of Maryland, Education Article, § 7-426 designates parents/guardians with certain responsibilities, including the following:

- School notification of a child’s special health care needs or diagnosis;
- Providing appropriate medication and delivery devices and medical condition indication devices including Medic Alert bracelets or necklaces which may include:
 - Annual physical exam from the student’s primary care provider/medical home;
 - A comprehensive eye examination by an optometrist or ophthalmologist;
- Parental consent for the administration of medications; and
- Providing emergency card or medical emergencies with current contact names and telephone numbers.

It is important that school nurses and parents/guardians work collaboratively to provide for the health and safety of students with special health needs. School nurses should seek to involve the student’s parents/guardians to the fullest extent possible.

STUDENT RESPONSIBILITIES

The student is integral to the process of coordinating and managing his or her own care. The student will:

- Inform school staff immediately in the event of a change in health status/health emergency;
- Act responsibly with SCD management; and
- Participate in planning of care.

SCHOOL RESPONSIBILITIES

The Annotated Code of Maryland, Education Article, § 7-426 specifies certain school and school administrator responsibilities for the care of students with special health needs. School administrators should work closely with school nurses in planning for students. The school administrator and school nurse should collaborate in gathering, maintaining, and reviewing school-wide information required to meet the needs of students. School nurses should provide aggregate data to the school administrator regarding the students with special health needs in the student population and the accommodations necessary to meet those needs.

The school administrator must be aware of students with special health needs as documented by a healthcare provider and work with the school nurse to support the effective implementation of the IHP and/or ECP for students. Implementation of the IHP and/or ECP includes supporting reasonable accommodations based on the school nurse’s assessment, healthcare provider orders, and the unique needs of each student.

SCHOOL ADMINISTRATOR RESPONSIBILITIES

The school administrator supports the school nurse’s training, education, awareness activities, and is responsible for:

- Recognizing the school nurse as the leader and health expert of the school health services program;
- Supporting the school nurse in providing staff training;
- Supporting the school nurse’s planning for implementation of student Emergency Care Plans during school sponsored events;
- Supporting the school nurse in providing outreach and education for parents/guardians and the general school community; and
- Supporting the school nurse in regards to adherence to the parent/guardian responsibilities.

OTHER SCHOOL STAFF RESPONSIBILITIES

Other school staff responsibilities to support the management of students with special health needs may include, but are not limited to the following:

| Other school staff | Responsibilities |
|--------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Bus Drivers | <ul style="list-style-type: none"> • Reading and understanding all pertinent health care information provided by the school nurse regarding a student’s SCD management; • Implementing the student’s ECP as instructed and/or trained by the school nurse; and • Communicating problems or concerns with the transportation office, school nurse, school administrator, and parent/guardian as instructed or trained. |
| Coaches, Athletic Trainers, and Advisors for School Sponsored Activities | <ul style="list-style-type: none"> • Communicating to the school nurse students with SCD as indicated on a pre-participation sports physical; • Understanding all pertinent healthcare information provided by the school nurse regarding a student’s SCD and SCD management; • Responding to emergencies during athletic or other activities as instructed and/or trained by the school nurse; and • Communicating problems or concerns to the school nurse and school administrator as instructed or trained. |
| Food Services Staff | <ul style="list-style-type: none"> • Reading and understanding all pertinent healthcare information provided by the school nurse regarding a student’s SCD management related to dietary needs. |
| School Counselor | <ul style="list-style-type: none"> • Coordinate Home and Hospital referrals • Participating in disability awareness activities as necessary; • Assisting with support groups/counseling as needed; and • Assisting with educational planning (e.g., collaborating with the student services team on Section 504 plan development and implementation). |
| Pupil Personnel Worker | <ul style="list-style-type: none"> • Assisting the school nurse to work with families to address transportation concerns. |
| School Psychologist | <ul style="list-style-type: none"> • Assisting the student with psychological supports for coping, adjustment, and any behavioral strategies. |
| Teachers (including substitute teachers) | <ul style="list-style-type: none"> • Reading and understanding all pertinent healthcare information provided by the school nurse regarding a student’s SCD management; • Maintaining and reviewing an accurate substitute folder; • Being aware of the classroom needs (e.g., routine care and emergency care) and Section 504 plans for students with SCD; • Responding to an emergency as instructed and/or trained by the school nurse; and • Communicating problems or concerns to school nurse, school administrator, and parent/guardian as instructed or trained. |

SCHOOL STAFF AWARENESS AND EDUCATION

School-wide awareness and education regarding SCD management for school staff is necessary in the school setting. Awareness and education may include, but is not limited to:

- Definition and types of SCD;
- Effective SCD management principles;
- Symptoms of a SCD crises to report to the school nurse;
- Student’s emergency care plan/protocol;
- Student’s emergency plans and protocols for substitutes including teacher, school health staff, transportation, coaches, and food services;
- Necessary and approved accommodations during school or school-sponsored activities;
- Confidentiality protections;
- Disability awareness needed in classroom;
- Student’s Section 504 plan or IEP; and
- Education for school visitors or volunteers with student contact, as necessary per local policy.

School staff awareness and education should be completed annually and whenever a student’s condition and care changes.

SCHOOL-SPONSORED ACTIVITIES AND FIELD TRIPS

If a school-sponsored activity is planned, the assigned school staff should provide sufficient notice to the school nurse to develop a safety plan for students with special health needs. According to the Americans with Disabilities Act Section 504 of the Rehabilitation Act of 1973, all students have the right to equal access to educational activities. No student may be denied participation in a field trip or other school sponsored activity because of the need for medication/treatment or requirement of additional assistance. Prior to the school-sponsored activity, the school nurse will provide the assigned school staff with a copy of the ECP. The school nurse will provide the appropriate training and assess the school staff’s ability to implement the plan.

SECTION IV: EDUCATION PLANNING

A nursing appraisal/assessment is a recommended part of the process for determining accommodations for students with special health needs as documented by the healthcare provider. Considerations include, but are not limited to:

- Participation in Section 504/IEP team;
- Adaptations to physical education class;
- Concurrent or intermittent home and hospital instruction; and
- Change in school placement.

INDIVIDUALIZED EDUCATION PROGRAM (IEP), SECTION 504 PLAN AND OTHER ACCOMMODATIONS

According to Section 504 of the Rehabilitation Act of 1973, all students with disabilities who are eligible under Section 504 are entitled to have access to a free and appropriate public education (FAPE). This entitles students to necessary accommodations for them to have an equal opportunity to safely participate in all school-sponsored activities. No student may be denied participation in these school-sponsored activities on the basis of their needs for SCD management. The following should be considered when developing a Section 504 plan or IEP for a student with SCD to protect the health and safety of the student and to be sure the Section 504 plan or IEP meets the medical needs of the student with SCD:

- Vocational assignment;
- Physical education;
- Field trip/school sponsored activities;
- Transportation to and from school;
- Methods/strategies to minimize lost instructional time;
- Extra and co-curricular activities; and
- Methods/strategies for students to obtain educational content because of missed instructional time related to SCD.

Examples of accommodations that should be considered by the Section 504 or IEP team for students with SCD in accordance with the student's SCD plan/healthcare provider orders and school nurse assessment include, but are not limited to:

- Easy/immediate access to water;
- Training of school staff to administer medications (based on school nurse assessment and nursing judgment);
- Extended time to complete academic work (e.g., quizzes, exams, standardized testing);
- Workload considerations;

- Extra set of books for home;
- No penalty for absences or tardiness due to SCD management activities or illness;
- Modified or limited PE participation;
- Unrestricted use of the restroom;
- Elevator access;
- Modification for environmental and/or classroom temperature control;
- Ability to wear coat or hat when necessary; and
- Permission to visit the health suite as needed.

This list is not exhaustive nor is it meant to suggest that these accommodations are required, or appropriate, for all students. Accommodations for any particular student will vary based on an individual assessment specific to each student. This general summary does not constitute legal advice. School nurses should contact their local school health services coordinator and/or the student services team to ensure they comply with state and federal law, as well as school system policies in developing a Section 504 plan or IEP.

SECTION V: SCD EVALUATION AND MONITORING

The school nurse should evaluate and monitor the SCD management activities in the school. The school nurse must assess the student's response to, and effectiveness of, the emergency plan and/or IHP to meet the student's health and educational needs on an ongoing basis. Monitoring and evaluation may result in establishment or revision of emergency plans and/or IHPs. For students with a Section 504 plan or IEP, a school nurse may need to coordinate with a case manager or other school system officials to ensure proper implementation of those plans.

Evaluation and monitoring of SCD management may include, but is not limited to:

- Orders reviewed with parents/guardians and health care provider annually and as necessary (e.g. medication or care needs changes);
- Documentation of medications and treatments given;
- Communication with the health care provider and family;
- Documentation of the specific school staff trained to provide or support routine SCD management and/or respond in an emergency to SCD crisis;
- Classroom observation;
- Monitoring classroom time missed;
- School absences; and
- Academic performance.

These guidelines are intended for use in public schools regarding the administration of health care services to students with SCD. Additionally, the Annotated Code of Maryland, Education Article §7-444 requires the MSDE and the MDH to provide technical assistance to schools and develop a process to monitor the implementation of the guidelines. The MSDE and MDH will continue to provide technical assistance and guidance to the local school health services programs for the implementation of the guidelines at the local school system level. Additionally, each local school health services program will be required to report on the local implementation of the guidelines for SCD management in the school setting.

SECTION VI: GLOSSARY, RESOURCES, REFERENCES

GLOSSARY

Americans with Disabilities Act of 1990, As Amended (ADA): A federal law that protects people with disabilities from discrimination.

Section 504 plan: An education plan developed by a school team for a student with a disability in accordance with Section 504 of the Rehabilitation Act of 1973 and 34 C.F.R. Part 104 that specifies services designed to meet the student's individual educational needs so the student can access a free and appropriate public education (FAPE).

Accommodations: Individualized changes or adjustments in a school setting that provide a student with a disability equal opportunity to participate in school programs and activities.

Emergency Care Plan (ECP): A document that specifies the actions needed to manage a student's specific medical condition in the event of a medical emergency.

Family Educational Rights and Privacy Act (FERPA): A federal law that, with certain exceptions, prohibits schools from disclosing personally identifiable information in a student's education record, unless the school obtains prior written consent from the student's parent/guardian or from the eligible student (i.e., a student who is 18 years or older or who attends an institution of postsecondary education).

Free and Appropriate Public Education (FAPE): Education provided by public schools to students with disabilities designed to meet their individual needs to the same extent that the needs of nondisabled students are met. An appropriate education may include regular or special education and related aids and services to accommodate the unique needs of individuals with disabilities.

Healthcare provider: An authorized prescriber. A physician, nurse practitioner, certified midwife, podiatrist, physician's assistant or dentist.

Individualized Education Program (IEP): A written document required under the Individuals with Disabilities Education Improvement Act (IDEIA) for students with disabilities that outlines their need for special education and related services.

Individualized Health Plan (IHP): A type of nursing care plan developed by the school nurse utilizing data from a nursing appraisal/assessment that is specific to a student with a chronic health condition and designed to meet the student's unique health care needs.

Individuals with Disabilities Education Act (IDEA): A Federal law that provides funds to states to support special education and related services for children with disabilities, administered by the Office of Special Education Programs in the U.S. Department of Education. To be eligible for services under IDEA, a student's condition must impair his or her educational performance so that

he or she requires special education and related services. IDEA also contains specific confidentiality protections for student records.

Nurse Practice Act: A statute enacted by the legislature of any state or by the appropriate officers of the district that delineates the legal scope of the practice of nursing within the geographical boundaries of the jurisdiction. The Maryland Nurse Practice Act is codified in the Annotated Code of Maryland, Health Occupations Article, Title 8. The accompanying regulations are found in the Code of Maryland Regulations Title 10, Subtitle 27.

Nursing appraisal: The process by which a designated school health services professional identifies health problems that may interfere with learning. These may include health observations, interviews, and conferences with parents/guardians, students, educators, and other health professionals.

Nursing assessment: The act of gathering and identifying data that assists the nurse, the client, and the client’s family to identify the client’s health concerns and needs. (Nurse Practice Act, Annotated Code of Maryland, Health Occupations Article, Title 8; COMAR Title 10, Subtitle 27.)

School nurse: A registered nurse currently licensed by the Maryland Board of Nursing who works in a school setting.

School-sponsored activities: Academic and non-academic school programs and activities at schools that receive federal financial assistance and are therefore subject to Section 504 of the Rehabilitation Act of 1973 (see [34 C.F.R. part 104](#)). These activities are those the student attends as a participant and not those attended as an observer.

Unlicensed School Staff: Non-medical school staff who are not part of the school health services program and meet the definition of an “Unlicensed Individual” under Code of Maryland Regulations 10.27.11.02 (24). This may include, but is not limited to, teachers, coaches, athletic trainers, administrators, and cafeteria workers.

RESOURCES

American Journal of Preventative Medicine: Developing a Unified Approach for Sickle Cell Disease, July 2016, Volume 51, Issue 1, Supplement 1, S1-S100

[https://www.ajpmonline.org/issue/S0749-3797\(16\)X0014-1](https://www.ajpmonline.org/issue/S0749-3797(16)X0014-1)

Centers for Disease Control and Prevention (CDC): Sickle Cell Disease

<https://www.cdc.gov/ncbddd/sicklecell/index.html>

“Living with Sickle Cell Disease- Self-Care Toolkit”

https://www.cdc.gov/ncbddd/sicklecell/documents/LivingWell-With-Sickle-Cell-Disease_Self-CareToolkit.pdf

“Tips for Supporting Students with Sickle Cell Disease”

https://www.cdc.gov/ncbddd/sicklecell/documents/tipsheet_supporting_students_with_scd.pdf

Genetics Education Materials for School Success (GEMSS): Sickle Cell Disease at a Glance

<https://www.gemssforschools.org/conditions/sickle-cell-disease/default>

Huntsville City Schools: Management Plan for Sickle Cell Disease

https://www.huntsvillecityschools.org/sites/default/files/sickle_cell_IHP_.pdf

Maryland Department of Health, Office of Genetics and People with Special Health Care Needs: Sickle Cell Disease Resources and Links

https://phpa.health.maryland.gov/genetics/Pages/SickleCell_Resources.aspx

Maryland Sickle Cell Disease Association

<http://www.marylandsicklecelldisease.org/>

Specialized Health Needs Interagency Collaboration

<https://www.kennedykrieger.org/community/initiatives/specialized-health-needs-interagency-collaboration>

St. Jude Children’s Research Hospital: Educational Resources for Sickle Cell & Other Blood Disorders

<https://www.stjude.org/treatment/disease/sickle-cell-disease/educational-resources.html>

“Educator’s Guide to Sickle Cell Disease”

https://www.stjude.org/content/dam/en_US/shared/www/patient-support/hematology-literature/educators-guide-to-scd.pdf

The New England Pediatric Sickle Cell Consortium (NEPSCC)

<http://nepsc.org/>

Virginia Department of Health: Virginia Sickle Cell Awareness Program

<http://www.vdh.virginia.gov/sickle-cell-programs/>

“Understanding the Child with Sickle Cell Disease: A Handbook for School Personnel”

http://www.vdh.virginia.gov/content/uploads/sites/64/2016/12/SchoolHandbook_SickleCellChild_PDF1.pdf

The Nemours Foundation: Fever in Children with Sickle Cell Disease

www.nemours.org

REFERENCES

¹Americans with Disabilities Act of 1990, As Amended (ADA).
<https://www.ada.gov/pubs/adastatute08.pdf>

² Rehabilitation Act of 1973, Section 504. Available at:
<http://www2.ed.gov/about/offices/list/ocr/504faq.html>

³ Individuals with Disabilities Education Improvement Act (IDEIA).
<https://www.wrightslaw.com/idea/idea.2004.all.pdf>

⁴ Annotated Code of Maryland, Education Article §7-444- Guidelines Regarding the Administration of Health Care Services to Students with Sickle Cell Disease

^{5,6,7,8,10,12,14} Centers for Disease Control and Prevention (CDC): Sickle Cell Disease (SCD)
<https://www.cdc.gov/ncbddd/sicklecell/facts.html>

^{9,11,13,15} National Heart, Lung, and Blood Institute (NHLBI): Sickle Cell Disease
<https://www.nhlbi.nih.gov/health-topics/sickle-cell-disease>

¹⁶ The New England Regional Genetics Network: Genetics Education Materials for Student Success (GEMSS)- Sickle Cell Disease at a Glance
<https://www.gemssforschools.org/conditions/sickle-cell-disease/default>

¹⁷ American Stroke Association
<https://www.strokeassociation.org/en/about-stroke/stroke-symptoms>

¹⁸ NANDA International
<http://www.nanda.org/>